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ABSTRACT

Nursing home patients suffering from dementia had a desire for placement in a setting where their special needs could be addressed. This resulted in the creation of special nursing home units designed to meet patient needs. Recent reports have provided evidence that nursing home residents suffering from dementia who receive care on these special units fare better than those on heterogeneous units on a variety of measures, demonstrating decreases in psychotropic drug use, accidents, and acting-out behaviors; and increases in orientation levels. While research has supported the contention that special care units for patients with dementia enhance the quality of life for the patients, the issues of quality of life may be more related to the patient's perception of outcome than to statistical findings. In future research, direct measures of quality of life should be included when assessing the outcome of special care units. The recipients of the care should be asked directly about their quality of life on the unit. While it has been argued that direct assessment of patients with dementia is impossible, research has been conducted which supports the procedure of an empathic assessor using the appropriate measure and having sufficient time to obtain valid responses. (Author/NB)

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ENHANCING QUALITY OF LIFE FOR PATIENTS WITH SPECIAL CARE NEEDS

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ABSTRACT

Recent reports have provided evidence that nursing home residents suffering from dementia who receive care on units designed to address their special needs, fare better than those on heterogeneous units on a variety of measures. These include decreases in psychotropic drug use, accidents, and acting-out behaviors. There is also some indication that orientation levels are increased. Among the initial reasons for designing special units was a desire on the part of patients for placement in a setting where their needs could be addressed. This presentation will explore these issues from the perspective of individual outcome, quality of life, and overall satisfaction with care in a specialized environment.

ENHANCING QUALITY OF LIFE FOR PATIENTS WITH SPECIAL CARE NEEDS

Approximately two decades ago, Schelling (1968) came to the important realization that when discussing outcomes to ultimate life events such as health and life and death that it would be wise to ask individuals for their preferences and consider those outcomes in probabilistic terms. This approach allowed for the development of a mathematical formulation, the Von-Neumann Morgenstern utility which established economic parameters for decision making in quality of life issues. More recently Neu (1982) expanded on Schelling's contribution by making the case that when discussing the issues related to long-term care there may not be a clear well-defined outcome. Outcomes may not exist at all in certain instances. What does exist are extended periods of differing lifestyles and "for many long-term care patients, changes in the way they are treated on a daily basis could be a lot more important" (p269). Thus it would be appropriate to understand, review and find a way to measure overall satisfaction with daily care in individual's daily lives. The goal of this procedure then is to focus primarily on asking patients what they feel they need in a long-term care setting to help define their perspective on appropriate care related issues.

Little research was done before 1980 into the best types of service including who should provide the care, patient staff-ratios and so forth in long-term care facilities (Cavaiola & Young, 1980). However, the concept of progressive patient care is one that has been receiving increasing attention particularly in the area of long-term care for the elderly.

One issue recently addressed along these lines is the question of how best to place patients in these facilities by need for care or availability of a bed (Ablowitz, 1983; Salamon, 1983). Arguments exist both pro and con on this issue. In favor of integrating patients on general units are those who suggest that this approach may have a beneficial impact on overall levels

of functioning. The arguments against include the enhanced ability of tailoring treatment and intervention programs when patients are matched by clinical status on units specifically geared to their needs and that integration of patients with different clinical needs may cause the healthier ones to avoid the impaired ones for fear of becoming more ill (Bowker, 1982). Indeed, several studies have found this to be the case in domiciliary care facilities where rates of socialization decreased when mentally impaired residents were combined with other healthy residents (Salamon & Nichol, 1980; Sherman & Snider, 1981).

In a recent study in a large skilled nursing facility over 600 patients and their care takers were surveyed regarding this issue (Salamon, 1983). The overwhelming preponderance of findings both from questionnaires and interviews with patients and staff indicated that not only the patients themselves but staff preferred the concept of living and working on units with individuals who have similar levels and types of impairments.

In response to this particular study a special care unit was established for patients suffering from moderate to severe dementia related behavioral and cognitive impairment. The primary goal of this project was to provide enhanced care targeted specifically at the needs of this particular sub-group of long-term care patients (Grossman, et.al. 1985).

Measuring outcome or improvement as a result of this change is a thorny methodological matter. Yet, it must be understood that in an entropic system lack of decline is often the best sign of improvement. Thus the best outcome measure might be to show that the anticipated rate of cognitive decline is interrupted by the intervention. This indeed was the major parameter by which outcome was initially to be assessed in this project.

Interestingly, however, a variety of secondary measures began to show some significant changes in a positive direction. Not only was the patients rate of cognitive decline apparently slowing down but the average number of monthly accidents declined from 16 to 10 over the first six months. Furthermore, the rate of use and dosages of psychotropic medication was comparable to a unit where patients were placed heterogenously thereby suggesting that behavior was not only not worse, but perhaps improved. Also, despite the greater number of patients with dementia chemical control was not a necessity. Concomitantly, the reported rates of aggressive patient behavior declined as did the number of patients screams, an annoying sign of confusion in the severely demented.

In a related study of a dementia unit in a different nursing home similar results were found. In this particular study (Benson, et. al., 1987) patients were found to have not only not deteriorated cognitively at one year follow-up but surprisingly to have an increased level of functioning both mentally, emotionally and in their ability to perform activities of daily living.

These two studies are among the first of a growing number of reports in which relatively hard data is being mustered to support the contention that special care units for patients with dementia enhance the quality of life for the patients who reside there. Yet as Neu suggested, the issues of quality of life may be more related to the patients perception of outcome than hard statistical fact. To be able to access the patients feelings on this important topic requires the care provider and researcher to seriously attempt to obtain that information from the patient directly. There is, however, a great deal of resistance to this approach as the feeling remains that cognitively impaired

individuals cannot provide the proper information. One should not, however, be surprised by the available cognitive skills of an individual suffering from a mild to moderate dementia when he or she is sufficiently oriented to respond appropriately to what more alert individuals consider an extensive interview. The amount of stimulation offered by the evaluative process might indeed serve as an orienting mechanism, drawing upon long-term memory, well rehearsed and deeply ingrained skills, ideas and feelings. It is true that concentration may wander and several sessions may be necessary to complete an interview which would take but a few moments in a less cognitively compromised individual but more often than not, individuals with mild to moderate dementia become actively involved in the evaluative process and provide important insightful information. At the very least, it has been well established that the cognitive symptoms which define the dementia syndromes differ from time to time in any given individual (Folstein & Rovner, 1986). Thus if a patient cannot respond at one point in time, he or she may be able to at the next.

Among some of the important findings in the area of quality of life is the recognition that patients suffering from dementia respond more appropriately to care providers who approach them empathically (Folstein & Rovner, 1986). Thus one goal for the provision of care to these patients is to find care providers who are able to develop empathic relationships. These care providers should also have the ability to interact with patients in spite of their limited cognitive and emotional skills.

Assuming the veracity of these findings that dementia suffers can express themselves to these empathic care providers in a fashion consistent with expressing appropriate care needs and being understood, than an equivalent amount of validity

should be ascribed to some of the recent findings on the reports of quality of life derived directly from these patients. In a somewhat related study (Salamon, 1986) in which the stability of personality in patients' dementia was assessed, dementia patients themselves were asked to take part in an extensive interview. The interview consisted of a series of open ended questions and the 16 PF, form C. All of the subjects had moderate cognitive impairment as measured by the MSQ and the Folstein Mini Mental status exam. Key family members of these patients were also asked to respond to the same interview as their ill family member would have. Rates of agreement between the ill patients and their family member for the personality factors A - cool vs. warm, B - concrete vs abstract thinking, C - affected vs. emotionally stable, H - shy vs. bold, L - trusting vs. suspicious, M - practical vs. imaginative, N - forthright vs. shrewd, Q2 - group oriented vs. self-sufficient and Q4 - relaxed vs. tense were all above 70 percent. Though the family members all completed the interview process in one sitting and the patients required two or three, the consistency of reports were all quite high , further confirming that despite cognitive impairment, if patients with dementia are provided with the proper setting and support, they can produce valid information about how they view themselves.

Interestingly, in the survey process for the evaluation of the provision of care to patients in skilled nursing care facilities a new category, "quality of life", has recently been added by some states. This quality of life is defined as a review, albeit process oriented, of a patient's degree of self-reported autonomy, dignity, privacy, respect and individual rights.

While a great deal of understanding for the broad concept of quality of life has been expressed, there is very little agreement as to what the precise mode of measurement should be. In a very real sense though, the measure of one's satisfaction with daily activities, well-being, mood and related variables may operationally form a measure of life's quality. If this is the case than the concept of life satisfaction, in its various forms, is a fair correlate of quality of life and, therefore, a good measure thereof. And, if this is indeed the case than measuring an individual's satisfaction with life is a fair indication of their perception of the quality of their life. In fact, many studies have used life satisfaction scales to measure how individuals feel in their daily lives in general or in response to specific programs or interventions (Larson, 1978). It is, therefore, no leap of faith but rather a simple extension of accepted practice to use a measure of life satisfaction to assess how demented individuals view the quality of their lives in response to receiving care on a unit specialized to meet their needs.

Several measures of life satisfaction have been used over the past 40 years. While they have the strength of years, they do not all present with strong psychometric properties nor do they assess the broader aspects of life satisfaction (Kane & Kane, 1981).

In response to this perceived need, a new scale was recently designed to perform reliably in a number of settings. The Life Satisfaction in the Elderly Scale (LSES) (Salamon & Conte, 1981; Salamon & Conte 1984) was designed as a multi-factor scale to measure the entire domain of life satisfaction and thereby quality of life in older adults. It was hypothesized that the construct life satisfaction consists of eight factors. The eight

factors which make up the LSES are pleasure in daily activities, meaningfulness of life, goodness of fit between desired and achieved goals, mood tone, self-concept, perceived health, financial security and social contact. Reviews of the literature indicate that these eight factors are important contributors to the sense of satisfaction with life's overall quality (Larson, 1978; Spreitzer & Snyder, 1974).

Several studies have found the LSES to be a reliable and valid measure of life satisfaction in a variety of settings (Brockett, 1987; Conte & Salamon, 1982; Salamon & Conte, 1983). In one study 41 patients residing in a skilled nursing facility referred for psychotherapeutic intervention were given a complete psychological and psychiatric intervention (Salamon, In press). The patients were also evaluated on their satisfaction with life using the LSES. Of the 41 residents, all had a psychiatric diagnosis coded as part of the reason for referral. These diagnoses included adjustment disorders, affective disorders, schizophrenia (usually in remission), and/or a dementia related diagnosis (OBS, OMS, SDAT, MID). All residents were verbal though 30% (N=12) had some degree of nominal aphasia, and only 25% (N=10) were completely oriented in all three spheres. The remaining individuals were mildly disoriented to time (N=30) and some (N=9) were disoriented to place. The average age of the residents was 82, with a range of 67 to 98 years. The average total LSES score was 118 which, according to the normative standard, is at approximately the 35th percentile for the age range over 80. This average score is also lower than that achieved by several other groups of skilled nursing facility residents whose average score was 137 (Salamon, 1987). This, in and of itself, may further suggest that the total LSES score is related to a sense of well-being whereby those referred for psycho-therapeutic intervention achieve average scores that are

lower than those not referred for such services.

The title of this paper enhancing quality of life belies the true purpose of my presentation which is to convince all prospective future researches to include direct measures of quality of life when assessing the outcome of special care units. By direct, I mean directly asking the recipient of care. In my own research, at this point, we have assessed about 60 individuals of whom 40 were approved for transfer to a special care unit for patients with dementia. We do not have six month follow-up data yet but a review of baseline LSES scores indicates that these individuals certainly need to have the satisfaction with their lives improved. The overall average LSES score prior to transfer to specialized care for these persons was 116, also approximately at the 35th percentile.

To summarize than: to those who would argue that secondary measures of improvement as a result of specialized care are sufficient, I argue Neu's position; the individual receiving the care, especially in the long-term care setting should be questioned. To those who would argue that direct assessment of patients with dementia is impossible, I respond with my own findings which support the use of this procedure, that is, an empathic assessor with the appropriate measure and sufficient time can obtain valid reponses. There is no question in my mind that just as in some of the other secondary outcome measures of special care units for patients with dementia show improvement, so too will quality of life measures. I also believe that we have a moral responsibility to obtain this information from the patients we are trying so hard to help. If we are to enhance quality of life than we must measure it appropriately and understand it.

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